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ORIGINAL REPORT

IMPROVING THE MANAGEMENT OF POST-STROKE SPASTICITY: TIME FOR ACTION

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Objective: To identify barriers to appropriate referral and treatment for patients with spasticity and present solutions that address these in a pragmatic way.

Methods: Using the findings of interviews conducted with UK healthcare professionals on the management of post-stroke spasticity, a consensus meeting was held involving 7 UK spasticity experts. The panel identified barriers to timely identification and referral of patients in the acute and post-acute care settings. Barriers were prioritized using a consensus framework based on impact and resolvability and a series of final recommendations were agreed. **Results:** High-priority barriers broadly related to: insufficient awareness of spasticity symptoms and benefits of treatment, limited access to spasticity services and lack of standardized pathways for post-stroke spasticity identification. Potential solutions included the appointment of an experienced member of the acute team to gain expertise in spasticity identification, patient education of spasticity symptoms and a greater utilization of training resources for healthcare professionals.

Conclusion: To address the barriers identified, we provide a series of consensus recommendations. As a key recommendation, we propose a set of indicators for the identification of stroke patients requiring specialist assessment and the use of the associated acronym "ACTION".

Key words: stroke; post-stroke spasticity; rehabilitation; health services; patient; physiotherapy.

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LAY ABSTRACT

People who have a stroke may suffer from complications such as spasticity (stiffness in muscles due to muscle contraction). Spasticity can cause difficulty with day-to-day activities and may also cause pain. People with stroke may have spasticity without it being diagnosed, and people who need treatment may not be seen by healthcare professionals. Through formal consultation and analysis with expert doctors, physiotherapists and occupational therapists a range of simple and practical recommendations to help improve treatment is proposed. An acronym 'ACTION' was developed, referring to limitation of Activity, difficulty with Care tasks, Tight muscles, Integrity of the skin, Ongoing pain and Nails digging in (to the palm of the hand). The acronym was designed to help clinicians identify spasticity following a stroke that might cause problems. The recommendations from the expert group are focused on clinical practice in the UK but are applicable to other countries and healthcare systems.

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Spasticity is a common feature of many neurological disorders, such as stroke. It is part of the upper motor neurone syndrome and it manifests as increased muscle tone associated with spasms and/or clonus (1). First described as "a velocity-dependent resistance to passive

movement with exaggerated tendon jerks resulting from hyperexcitability of the stretch reflexes" (2), it has more recently been defined as "disordered sensorimotor control, resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles" (3), which more accurately reflects the clinical presentation and is the definition used in this paper.

Epidemiological studies have shown that up to 38% of stroke patients are affected by spasticity (4), which equates to more than 40,000 newly affected patients with post-stroke spasticity (PSS) per year in England alone (5). Onset of spasticity can occur at any time after stroke (6). The estimated prevalence of PSS is 21% in the first week (7), 19% at 3 months, 22% at 4 months, 43% at 6 months (8) and 17–46% at 12 months post-stroke (9–11). Sensorimotor function has been found to be the most important predictor for any, or severe, spasticity (12). Spasticity could be predicted with 85% sensitivity and 90% specificity 10 days post stroke using a prediction model (12).

Spasticity has a negative impact on post-stroke physical and mental wellbeing, as it contributes to functional limitations, including difficulties with personal hygiene and mobility, with subsequent implications for societal participation and quality of life. As a result, patients can experience depression, anxiety and poor self-esteem (13, 14), while their caregivers may also be affected by depression and anxiety due to the considerable burden of care placed upon them (15).

Patients with spasticity are at risk of developing secondary complications, including contractures and pressure sores (16). Complications can emerge as early as 4 weeks post-stroke (13), so it is essential that spasticity is recognized early and an appropriate management plan put in place. Early intervention may help to prevent complications that impede patient rehabilitation and may facilitate more functional outcomes in some individuals (13). Effective spasticity management requires a multidisciplinary approach that combines physical rehabilitation (including postural management) with, if necessary, pharmacological interventions (16).

Recent analyses have revealed significant under-recording of PSS in primary care data, reflecting likely under-diagnosis or under-reporting of the condition (17).

Notably, in contrast to other common post-stroke complications, the UK Sentinel Stroke National Audit Programme (SSNAP) does not specifically monitor spasticity at any point in the stroke patient journey. Furthermore, there is no nationally agreed pathway for PSS, and a general lack of formalized protocols for the identification, monitoring and referral of patients with PSS or at high risk of developing the condition. As a result, patients with PSS are often only referred for spasticity treatment once secondary complications have arisen. Moreover, an unknown number of patients with problematic spasticity may receive no treatment at all, because their spasticity has not been identified.

In view of these challenges, an expert consensus panel was convened to: (i) assess the barriers to timely identification and referral of patients; and (ii) identify potential solutions to optimize management of PSS.

METHODS

A consensus meeting was held involving a multidisciplinary panel comprising 7 UK expert spasticity practitioners, drawn from acute stroke, secondary and tertiary rehabilitation, intermediate and community care (2 consultant neurologists, 2 consultant physiotherapists, 1 consultant in stroke medicine, geriatrics and general medicine, 1 consultant in rehabilitation medicine, 1 advanced occupational therapist). The aim of the meeting was to discuss barriers to the identification and referral of patients with PSS and propose solutions to overcome them.

The panel used findings gathered from in-depth 1-h telephone qualitative interviews with 12 healthcare professionals (HCPs) (from across the UK) selected based on their knowledge, skills and working in the field of spasticity. Structured interviews were carried out to gain insights into PSS referral and management practices in the UK and were conducted by 2 interviewers from a medical communications agency. Ten of the interviewees were based in acute care or hospital-based rehabilitation settings (2 consultant physiotherapists, 6 consultants in rehabilitation medicine, 1 consultant in neuro-rehabilitation and 1 consultant in geriatrics and stroke medicine), while 2 were based in the community rehabilitation setting (2 community physiotherapists). One of the interviewees was subsequently invited to become a member of the consensus panel. All interviewees were asked a set of questions based on the following topics: sources of patient referral, screening and assessment of patients, treatment goals, factors influencing referral and barriers to timely referral and treatment. Thematic analysis was undertaken by the interviewers and a report documenting the interview themes was compiled.

The consensus meeting was conducted as follows: (i) A round-table discussion was held based on the interview outcomes. (ii) The consensus panel was split into 2 breakout groups, focusing on acute and post-acute care. (iii) The 2 groups discussed and proposed barriers that hinder the timely identification and referral of patients with PSS in their setting. (iv) Each group prioritized the identified barriers diagrammatically based on impact and resolvability using implementation matrices. (v) The groups reconvened to present, discuss and refine the identified barriers. (vi) The panel split again into "acute" and "post-acute care" breakout groups to identify practical, implementable solutions to address those barriers deemed likely to have the greatest impact on patients and to be surmountable in the short term. (vii) The 2 groups reconvened and presented the proposed solutions to the full panel and the final recommendations to overcome the prioritized barriers were discussed.

All breakout and panel discussion sessions were facilitated by external moderators. Proceedings were audio recorded and the outcomes following the consensus meeting were consolidated into a draft paper.

RESULTS

In-depth interviews with UK healthcare professionals

Key findings from in-depth telephone interviews with 12 UK HCPs involved in spasticity management are summa-

Table I. Summary of findings from in-depth interviews with UK healthcare professionals

Topic areas	Themes from interviews
Sources of patient referral	<ul style="list-style-type: none"> Physiotherapists in acute care or the community are most likely to refer patients with PSS for treatment, whereas GPs rarely refer unless advised by a therapist Some spasticity centres do not accept direct referrals from physiotherapists; they must come via a GP Seven interviewees felt that some groups of patients might be less likely to receive a referral for specialist treatment than others, for example, elderly patients in nursing homes who may have cognitive difficulties, patients with communication difficulties, and frail patients who may have difficulty complying with physical therapy
Screening and assessment of patients	<ul style="list-style-type: none"> 8 out of 12 interviewees said that stroke patients are routinely assessed for spasticity while in acute care Assessment for spasticity on the acute ward is primarily carried out by physiotherapists
Treatment goals	<ul style="list-style-type: none"> Patients are rarely identified as being at risk of spasticity prior to spasticity onset Treatment goals for spasticity are mainly passive (though active treatment goals are relevant in some cases) and include improved hygiene, improved/maintained range of movement and preservation of skin integrity
Barriers to timely identification and treatment of patients with PSS	<p><i>Level of awareness</i></p> <ul style="list-style-type: none"> There is often insufficient awareness among HCPs outside the field of rehabilitation on the signs of spasticity, benefits of treatment and specialist spasticity services available Patients and their carers need to be educated about spasticity, the factors that can worsen the condition and the services and treatments that are available to help manage it High staff turnover in nursing homes can hinder measures to improve awareness of the signs of spasticity and benefits of early treatment Uncertainty among some HCPs regarding the effectiveness of some interventions may reduce the likelihood of referral <p><i>Lack of capacity</i></p> <ul style="list-style-type: none"> Capacity of specialist spasticity services varies greatly across the UK and lack of service capacity results in delays after referral Services are better developed in areas serving a larger population and with consequently larger numbers of patients more likely to be referred In some areas, individual services are not always well linked and communication between them is often limited reducing flexibility in service provision Nationally the number of stroke patients is increasing, which puts increased pressure on existing spasticity services <p><i>Other barriers</i></p> <ul style="list-style-type: none"> Emphasis on early discharge in the acute stroke setting means that most patients with PSS are referred after inpatient discharge and managed as outpatients, resulting in treatment delays Routine follow-up of stroke patients beyond the typical 6-week follow-up appointment is often limited. This reduces the opportunities for spasticity detection and referral Spasticity treatment is a small (but important) component of overall patient care and is not therefore identified as a primary focus for commissioning. In some cases, this means, individual funding requests are required for treatment with BoNT-A

BoNT-A: botulinum toxin A; GP: general practitioner; PSS: post-stroke spasticity.

rized in **Table I**. Barriers to timely patient identification and referral identified during the interviews included: lack of awareness on the signs of spasticity and benefits

of treatment among HCPs, patients and carers; limited capacity of services; inaccessibility or absence of services; and lack of adequate patient follow-up.

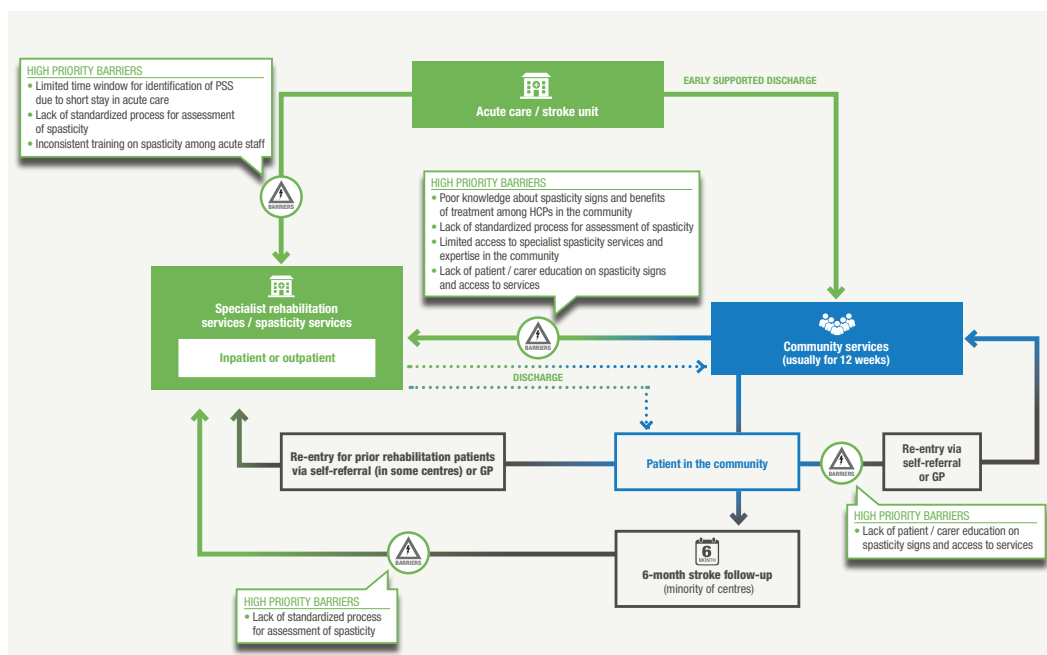
**Fig. 1.** Key barriers identified and prioritized during the consensus meeting and their positions within the patient journey.

Table II. Barriers and solutions proposed during the consensus meeting

Barriers	Potential solutions to high priority* barriers
<i>Barriers identified by acute care breakout group</i>	
High priority* <ul style="list-style-type: none"> Limited time window: time for identification and referral is limited by the short duration of stay in acute care Lack of a standardized stroke protocol specific for identification of PSS Several unvalidated spasticity measurement tools exist, but none are included in standardized stroke management protocols. Moreover, a gold-standard tool in assessing spasticity is currently lacking Inconsistent training: patients with PSS are sometimes missed due to insufficient knowledge and a lack of confidence to refer among some acute care staff Forward planning is limited 	<i>Potential solutions identified by acute care breakout group</i> <ul style="list-style-type: none"> Appointment of a "spasticity champion" on acute wards to connect with all teams and train acute care staff on spasticity identification Use of risk factors to identify stroke patients at high-risk of spasticity "Flag" high-risk patients to assure assessment for spasticity at patient follow-up Development of a standardized pathway for HCPs that can be tailored locally to optimize patient management
Low priority <ul style="list-style-type: none"> Acceptance of impairment as an inevitable consequence of stroke by patients, family and carers Low prioritization of PSS management by clinical commissioning groups Low prioritization of PSS management in primary care Long waiting lists for spasticity clinics or outreach visits Limited capacity for long-term follow-up of stroke patients 	
<i>Barriers identified by post-acute care breakout group</i>	
High priority* <ul style="list-style-type: none"> Poor knowledge among HCPs: insufficient awareness of spasticity symptoms and differential diagnoses leads to difficulties in making appropriate referrals Lack of a standardized process for spasticity assessment Limited access: access to specialist services is variable and often poor, hindering timely access. Some patients find it difficult to travel to secondary care clinics Lack of communication/joined-up working between services Lack of patient/carer education on spasticity Lack of specialist spasticity services in some areas Insufficient funding of community rehabilitation services Current spasticity services have limited capacity and time for inreach and outreach Staff managing stroke patients have competing demands, so spasticity is not prioritized Patients in care homes are missed because of insufficient awareness among care home staff caused by high staff rotation Patients are not empowered to seek help Small numbers of therapists (occupational therapists and physiotherapists) working under PGDs Referral processes are sometimes complex, e.g. a requirement that referrals come from primary care rather than directly from physiotherapists 	<i>Potential solutions identified by post-acute care breakout group</i> <ul style="list-style-type: none"> Provision of patient information leaflet including checklist that helps identify symptoms of PSS Pre-discharge conversation with patients/carers to educate patients on spasticity Spasticity passport carrying individualized patient information Greater utilization of existing training resources for HCPs Mentoring programmes for allied health professionals Telephone/email triage service to assist community HCPs in making appropriate referrals Telephone consultations to facilitate regular follow up of patients in the community Use of checklists containing risk factors and "indicators for action" for HCPs to identify patients requiring further assessment Empowering spasticity specialists to visit patients in the community in a consulting role
Low priority <ul style="list-style-type: none"> Staff managing stroke patients have competing demands, so spasticity is not prioritized Patients in care homes are missed because of insufficient awareness among care home staff caused by high staff rotation Patients are not empowered to seek help Small numbers of therapists (occupational therapists and physiotherapists) working under PGDs Referral processes are sometimes complex, e.g. a requirement that referrals come from primary care rather than directly from physiotherapists 	
<i>High priority* barriers agreed by panel</i>	
<ul style="list-style-type: none"> Lack of a standardized process for spasticity assessment in stroke patients Limited window of opportunity for identification of spasticity in acute care due to a focus on early discharge Inconsistent training of stroke staff resulting in lack of confidence in identifying spasticity and referring patients Lack of patient education regarding spasticity signs and access to services General lack of awareness of spasticity signs, differential diagnoses, treatments available and the benefits of treatment across all community HCPs Limited access to spasticity services and expertise in the community 	

*High-priority barriers are those considered by the panel to have a high impact on patients and to be resolvable in the short term within the current UK healthcare framework; all other barriers were considered low priority for the purposes of the consensus process.
HCP: healthcare professional; PGD: patient group direction; PSS: post-stroke spasticity.

Key barriers and potential solutions identified by the consensus panel

The barriers to timely referral and treatment of patients with PSS identified by the acute and post-acute care breakout groups are presented in **Table II**. Key barriers (existing throughout the patient journey) prioritized by the panel broadly related to lack of awareness and knowledge of spasticity, insufficient access to spasticity services and a lack of standardized processes/pathways (**Fig. 1**). Lack of awareness of spasticity among HCPs, and particularly how to identify it against a background of other musculoskeletal and biomechanical changes, was identified

as a key barrier at all stages of the patient journey. The potential solutions identified by each breakout group to address high-priority barriers are also listed in **Table II**.

DISCUSSION

Insufficient awareness of the signs of spasticity among some acute care staff means that patients who develop signs of spasticity in the acute setting are often discharged without a spasticity management plan in place.

Once discharged into the community, patient access to spasticity services and expertise can be limited by

the highly variable nature of spasticity service provision across the UK. Moreover, lack of patient education on spasticity means that patients experiencing spasticity onset following discharge are not empowered to seek help. Poor communication and insufficient integration between primary and secondary/tertiary care services in some areas further hinders access to spasticity services.

With the aim of improving clinical outcomes and quality of life for patients with PSS, we identified barriers that hinder the identification and referral of patients with PSS in the UK and are surmountable in the short term. We propose a set of practical recommendations which were agreed following extensive discussions and are shown in **Table III** and discussed further below.

To improve identification and management of PSS at all stages of the patient journey, we propose that HCPs use a set of “indicators for specific review and possible treatment” (**Fig. 2**). The simple nature of the proposed criteria should enable their inclusion in patient information leaflets and pre-clinic questionnaires to increase the likelihood of timely PSS following discharge. To assist HCPs in applying these criteria, we suggest the use of the acronym “ACTION” (**Fig. 2**).

As spasticity onset occurs more frequently after discharge from acute care, all stroke patients should be assessed on the acute ward for their risk of future spasticity and high-risk patients should be “flagged” to specialist rehabilitation teams for close monitoring after discharge. Therefore, we recommend that an experienced member of the acute multidisciplinary team (MDT) should liaise between the acute, specialist rehabilitation and commu-

Does spasticity (muscle tightness/muscle stiffness):	
A ctivities limited	Limit functional activities that you were able to do previously?
C are tasks difficult	Limit your or others' ability to carry out your personal care tasks?
T ight muscles	Reduce your ability to stretch or position your joints?
I ntegrity of skin	Lead to pressure sores on your skin?
O ngoing pain	Cause you pain or discomfort?
N ails digging in	Cause your nails to dig into the palm of your hand?

Fig. 2. Indicators for specific review and possible treatment of post-stroke spasticity (PSS) and associated acronym.

nity teams to gain not only increased expertise in PSS identification, but also to take responsibility in flagging high-risk patients.

Increased education on spasticity could empower patients developing signs of PSS to seek help, while a “patient passport” containing details of the patient’s stroke and any spasticity (and treatment(s)) could help to improve patient management following discharge into the community.

The introduction of telephone or email triage services would not only facilitate patient follow-up, but would also allow community HCPs to seek advice on patients with PSS or suspected PSS. These services, together with enablement of specialist spasticity clinic practitioners to visit patients in the community, could contribute significantly to improving access to specialist spasticity services.

Improving knowledge of spasticity among community teams with the use of existing training resources, particularly easily accessible online resources, should also serve to increase access to appropriate care.

Table III. Consensus recommendations to improve timely identification and referral of post-stroke spasticity patients

Implementation setting	Recommendation
All settings	<ul style="list-style-type: none"> Identification of patients with problematic spasticity within routine stroke care settings across the pathway. “Indicators for specific specialist spasticity review and possible treatment” have been identified and the corresponding acronym, “ACTION” (see Fig. 2), has been developed
Acute care	<ul style="list-style-type: none"> Appointment of an experienced HCP on the acute ward to act as a “spasticity champion” by liaising with specialist rehabilitation teams and taking responsibility for transfer of knowledge and skills to acute care staff Identification of patients at high risk of developing spasticity based on the criteria of severe stroke plus 2 or more of the following: severe motor weakness, severe sensory loss, communication impairment, unwell with other medical presentations, frailty, and neuropathic and/or other pain “Flagging” of high-risk patients to stroke and community teams, to facilitate close monitoring of spasticity onset prior to and after discharge from hospital Patient education (patient awareness and self-management) and their carers on the signs of spasticity, treatments available and action to take if they experience symptoms, through a pre-discharge meeting with a member of the acute team and provision of patient information
Community care	<ul style="list-style-type: none"> Provision of a patient passport containing details of the patient’s stroke, spasticity and any treatment(s) Inclusion of “indicators for action” in a pre-clinic screening questionnaire for patients to complete with assistance from an HCP (if necessary) prior to follow-up appointments Telephone triage services allowing community HCPs to seek advice from specialist spasticity services regarding patients Improve access to spasticity expertise by enabling specialist spasticity practitioners to carry out community visits Using existing online training resources to improve knowledge of spasticity among HCPs in the community
Specialist spasticity services	<ul style="list-style-type: none"> Telephone triage / email services to allow community HCPs to seek advice from specialist spasticity teams regarding patients Telephone consultations to improve follow-up of patients in the community who find it difficult to access specialist services due to travel difficulties Enabling specialist spasticity practitioners normally based in clinics to visit patients in the community (to assess patients and review results of treatment)

HCP: healthcare professional; PSS: post-stroke spasticity.

Limitations of our methodology

A limitation of this work included the relatively small number of respondents chosen for the in-depth interviews ahead of the consensus meeting.

Another limitation consisted in their selection process. Although respondents were chosen based on their expertise in PSS, further qualifying criteria, such as geographical representation or representation of all care settings and professional disciplines involved in the management of PSS management were not strictly applied (though were broadly considered).

Nonetheless, we hope that this paper will serve as a valuable discussion point for stroke services across the clinical pathway and that the recommendations we propose will serve as a useful foundation for improving current PSS services as well as for the development of formalized PSS pathways in areas where none currently exist.

Future perspectives

While the measures recommended in this paper may not all be applicable or implementable in every region, they provide a framework for PSS management improvement, individual aspects of which could be implemented depending on the services currently in place and the resources available. Some of these recommendations, for example telephone consultations, already operate successfully in individual centres, but could be rolled out more widely and established as standard approach.

Moreover, the recommendations herein presented could potentially be adapted and considered internationally.

In conclusion, we focused on barriers that could be realistically addressed in the short-term and on solutions that were practical within the current healthcare setting. A fundamental barrier that is not easy to address is insufficient funding, which limits the capacity and resources of spasticity services. However, earlier intervention in PSS could help to limit the costs associated with post-stroke management by reducing secondary complications and improving long-term outcomes. Cost-effectiveness evaluations to demonstrate the long-term benefits of effective spasticity management will be an important step towards the greater prioritization of spasticity treatment among commissioners of clinical services and to improve the management of PSS on a national scale.

Monitoring performance in spasticity management could increase accountability and provide an incentive for greater prioritization of spasticity care. In the UK setting, the creation of a national database to support the evaluation of performance and outcomes related to PSS management would be beneficial to this end. This will, however, require time and funding to establish. Inclusion of spasticity metrics in the SSNAP could help to drive improvements in PSS management. Meanwhile, we encourage HCPs to refer to up-to-date Royal College of Physicians national clinical guidelines (18) for recommendations to optimize patient management.

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Merz Pharma UK reviewed the final consensus paper for factual accuracy but responsibility for opinions, conclusions and interpretation of clinical evidence, and the submitted draft, lies with the authors.

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